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Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study

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Abstract

Background: Although nurses worldwide are confronted with euthanasia requests, how nurses experience their involvement in euthanasia remains unclear.
Objectives: To explore nurses' involvement in the care for patients requesting euthanasia.
Design: A qualitative grounded theory strategy.
Setting: Two general hospitals (A, B) and a palliative care setting in Flanders (Belgium).
Participants: Nurses who fulfilled the following inclusion criteria: (a) Dutch-speaking; (b) working for at least one year in hospital A or B; (c) working at least part-time ($\geqslant 50\%$); and (d) ever received a euthanasia request. We collected data using purposeful sampling, superseded by theoretical sampling in a palliative care setting. The sample included one intensive care nurse, one oncology nurse, eight palliative care nurses, and five internal medicine nurses. All but five were women. Their age ranged from 24 to 49 years.
Methods: We conducted one-on-one semi-structured interviews between November 2001 and September 2002. Grounded theory was applied for guiding data collection and analysis. The trustworthiness of data was ensured by several strategies.
Results: Although euthanasia was still illegal, the nurses unanimously stated that they had an important role in caring for patients requesting euthanasia. Their personal and intense involvement caused them to experience a spectrum of emotions, chief among them being a sense of powerlessness. Several elements contributed to the nurses' conflicted involvement. Nurses became frustrated if the context (e.g., lack of time) hindered their efforts to provide compassionate care. The palliative care setting and its associated culture (group mentality, care philosophy) created the opportunity for nurses to take time to holistically support patients and their relatives.
Conclusions: Hospital nurses are confronted with patients' euthanasia requests. Each stage of this process requires that the nurses possess specific competencies. Their willingness to personally care for these patients, in addition to their specific care expertise, allows them to be skilled companions.

keywords: Ethics; Euthanasia; Grounded theory; Nurses' involvement; Nursing; Qualitative research

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What is already known about this topic?

- Review of the literature from the Netherlands, Belgium, Australia, Japan, and the USA, as well as anecdotal experiences, show that nurses are involved in the care process surrounding euthanasia, regardless of the legal status of euthanasia in the country being studied.
- Although nurses worldwide are confronted with euthanasia requests, how nurses experience their involvement in euthanasia remains unclear.

What this paper adds

- An in-depth understanding of the experiences of Belgian nurses who are involved in the care for patients with a euthanasia request (prior to euthanasia legalization), using a qualitative research design.
- An in-depth understanding of the concepts influencing nurses' involvement in the care for patients with a euthanasia request and leading to unjustified variation in patient care.
- Demonstrating the impact of the nursing care context on nurses' experiences. Remarkably, we found that the care unit where the patient is hospitalized and its associated contextual elements significantly influenced the quality of nursing care that patients received. The palliative care setting and its associated culture (group mentality, care philosophy) created the opportunity for nurses to take time to care for patients and relatives in a professional manner.
- Demonstrating the need for support (legal, education, guidelines) of nurses in their role in caring for patients with a euthanasia request.

The Belgian Euthanasia Act (Ministry of Justice, 2002) came into force on 23 September 2002, making Belgium the second country—after the Netherlands—to decriminalize euthanasia under certain conditions. This Act permits physicians to perform euthanasia (i.e., administration of lethal drugs with the explicit intention of ending a patient's life at the patient's explicit request) without being subject to punishment. Unfortunately, the Belgian legislation has little to say about nurses' involvement in euthanasia, only stipulating that the patient's request must be discussed with the nursing team having regular contact with the patient. This short reference leaves nurses with many questions regarding their specific role in euthanasia.

The effects of living longer have profound effects on society, and hence, on healthcare. While nurses, and especially palliative care nurses, have the specific expertise to alleviate the suffering of terminally ill patients through high-quality care, no magic panacea exists. Nurses worldwide will continue to be confronted by ethically sensitive issues, such as euthanasia. A better understanding of how nursing expertise and competencies can be used most effectively in the context of interdisciplinary care requires an in-depth exploration of the experiences of nurses themselves. Greater awareness of and reflection on the specific roles and contribution of nurses in caring for patients requesting euthanasia could promote optimal nursing care for these patients.

1. Literature review

Although euthanasia was illegal in Belgium prior to approval of the euthanasia law, researchers have estimated that the percentage of all euthanasia deaths in Flanders (i.e., Dutch-speaking part of Belgium) ranged from 0.3% (van der Heide et al., 2003) to 1.1% (Deliens et al., 2000). Review of the literature from the Netherlands, Belgium, Australia, Japan, and the USA, as well as anecdotal experiences, show that nurses are involved in the care process surrounding euthanasia, regardless of the legal status of euthanasia in the country being studied. Nurses are often the first caregivers to receive a euthanasia request (Deliens et al., 2000; Bilsen et al., 2004; De Beer et al., 2004; van de Scheur and van der Arend, 1998; Verpoort et al., 2004a) and are intimately involved in the entire care process, starting from the patient's request through performing euthanasia to aftercare for the patient's relatives. Nurses listen to the patient's request; they report and explain the request to other caregivers; and they support patients, the patients' relatives, and the physician when lethal drugs are administered (De Beer et al., 2004). Review reveals further that their involvement in euthanasia depends on several contextual factors (e.g., legal context, euthanasia policy, physician's treatment policy and specialty, and institutional setting). More pragmatic factors such as time pressures and routines also seem to influence whether and how nurses are involved in the care process (De Beer et al., 2004). Bilsen et al. (2004) recently reported that hospital nurses in Belgium administered lethal drugs in 58.8% of euthanasia cases, most of which occurred in the absence of the prescribing physician. Although these nurses performed euthanasia within a palliative care context and after previous discussion with the physician, the finding that nurses themselves administer lethal medications should be taken seriously. Regardless of whether the physician may have delegated this act, this situation puts nurses in a precarious legal position, because, at the time of this study, euthanasia was illegal in Belgium. Because most are subordinate to physicians, nurses are in a poor position to refuse any involvement that lies outside the legal position offered to doctors. This finding is even more disturbing when one realizes that nurses are in the

best position to provide care for terminally ill patients because of their continual, intimate association with them. The willingness to personally and fully care for patients who request euthanasia is clearly present among nurses (De Beer et al., 2004; Verpoort et al., 2004b). Less clear from the empirical studies is how this willingness gets translated into care. The ongoing euthanasia debate, which has already resulted in euthanasia legislation in two countries, leads us to believe that nurses will be increasingly confronted with and involved in euthanasia. This literature review argues for greater clarity in the actual nursing practices related to euthanasia.

In anticipation of Belgian legislation on euthanasia, we interviewed nurses about their role in the care process surrounding euthanasia, regardless of whether it is actually carried out or not. This research was limited to euthanasia requests in terminally ill, mentally competent, adult patients. Euthanasia was still illegal then.

2. Methods

2.1. Design

A qualitative research design is necessary to explore in detail nurses' experiences about their involvement in caring for people who request euthanasia. Although the primary study aim did not include theory development, we selected a grounded theory approach (Strauss and Corbin, 1990) to guide our data collection and analysis because it has the potential to develop and refine theoretically relevant concepts leading to a better understanding of nurses' involvement in euthanasia.

2.2. Procedure and sample

The illegality of euthanasia requires both that the researchers provide a guarantee of confidentiality and that the participants respond candidly and truthfully. Therefore, we performed our study in two general hospitals in Flanders with which we have maintained a long-standing collaborative relationship in the field of ethics. We presented the study protocol to the ethics committees of these hospitals (referred to hereafter as A and B). After being granted permission to conduct our study, we selected and informed a contact person in each hospital. The contacts then approached nurses who fulfilled the following inclusion criteria: (a) Dutch-speaking; (b) working at least one year in a geriatric, oncology, intensive care, or palliative care unit (including members of palliative support teams (PST)); (c) working at least part-time; and (d) received a euthanasia request in the year prior to the study. Since we initially recruited only a small number of nurses, we broadened the criteria to make eligible all nurses working anywhere in hospital A or B, and who ever received a euthanasia request. Those nurses eligible and willing to participate gave their informed consent. Initially, we collected data using purposeful sampling. This approach was superseded by theoretical sampling as initial data directed how additional sampling should proceed. New information relevant to theoretical concepts continued to emerge, even after 10 interviews had been completed. To evaluate our hypotheses we enrolled new participants from a palliative care setting, with whom we have maintained a long-standing relationship in the field of ethics. These palliative care nurses were contacted by the researcher. After 15 interviews, an adequate saturation level was reached. Our final sample included 10 women and five men. Their age ranged from 24 to 49 years. The sample included one intensive care nurse, one oncology nurse, eight palliative care nurses (of whom three were PST nurses), and five internal medicine nurses. The participants' characteristics are summarized in Table 1.

2.3. Data collection

We performed one-on-one interviews between November 2001 and September 2002. These interviews were

Table 1
Characteristics of the participants ($n = 15$)

Setting—Hospital
Hospital A: $n = 8$
Hospital B: $n = 2$
Personal contact with nurses from palliative care setting: $n = 5$
Setting—Unit
Palliative care unit: $n = 5$
Palliative support team: $n = 3$
Internal medicine unit: $n = 4$
Oncology unit: $n = 1$
Oncology—internal medicine unit: $n = 1$
Intensive care unit: $n = 1$
Gender
Male: $n = 5$
Female: $n = 10$
Age
Range: 24–49 years
Position
Head nurse: $n = 2$
Nurse: $n = 13$
Working experience in nursing
Range: 1–19 years
Employment status
Part-time ($\geqslant 50\%$): $n = 5$
Full-time: $n = 10$

guided by open-ended questions that served as an interview guide, as well as a standard by which to assess the information obtained (Rubin and Rubin, 1995). The interviews lasted an average of 1 h. The first 10 interviews were conducted in a private area at the participant's workplace; the others were conducted at the nurse's home. All interviews were tape-recorded with participants' permission. To ensure the quality of questions, regular meetings with research supervisors were held. We integrated their valuable comments into the interview guide, which evolved over time.

2.4. Data analysis

The applied grounded theory approach consisted of isolating, comparing, conceptualizing, categorizing, and relating the data to each other (Strauss and Corbin, 1990). Initially, the transcripts and field notes were read several times, significant passages were marked, and concepts were assigned to words, sentences, or paragraphs. We coded the concepts initially using the participants' phrasing and grouped them into categories using the constant comparison method. Early conceptualizations were recorded in analytic memos. Finally, the data were organized into a framework by making first-degree connections between the categories. Coding was supported by the QRS NUD*IST N4 software program (Gahan and Hannibal, 1997). Trustworthiness was ensured by maintaining meticulous records of the interviews and of the investigator's personal impressions and by documenting the details of data analysis. Frequent meetings with the research supervisors were held, and an independent assessment and interpretation of transcripts by skilled qualitative researchers was carried out.

2.5. Ethical considerations

We presented the study protocol to the hospitals' ethics committee that granted us written permission. When theoretically sampling, we presented the protocol to the nurses. We respectfully maintained the anonymity of both the institution and the participants, and we treated all data confidentially. The recorded interviews were listened to and transcribed exclusively by the researcher. After the study was finished, the records were destroyed.

3. Results

3.1. The nurses' conflicted feelings about (their involvement in) euthanasia

Nurses felt intense moral conflict when patients requested euthanasia. Many nurses expressed concern about the exact meaning of the patient's words and questioned themselves whether there was a concealed appeal for help behind the request. Although they wondered what might be the reason for such terrible suffering, nurses were not always in favor of euthanasia.

Both the nurses' attitude towards euthanasia and the extent to which nurses—as professionals as well as individuals—allowed themselves to be touched by the euthanasia request were important. Nurses who supported euthanasia experienced powerlessness, because it was forbidden by law. On the other hand, opponents of euthanasia experienced difficulties because their patient's wish differed from their moral view of euthanasia. These nurses experienced intense internal conflict when confronted with their patient's suffering. They tried to act against the patient, and to seek an alternative solution. Nurses who allowed themselves to be touched experienced an inner struggle. These nurses were hard hit by this request and took it personally, causing them to question the meaning of life. The nurse's attitude to euthanasia was seldom clear-cut pro or con, resulting in ambivalent feelings.

> When I am confronted with a euthanasia request, there are always two sorts of feelings that crop up. [One is] the feeling of powerlessness, because I don't succeed in doing what I put first. I want to care for that person, but I am not successful, otherwise that patient wouldn't have requested to die. On the other hand, I partially understand that request, because patients will suffer more and more. Actually I agree with the patient's euthanasia request, but don't request me [to help in performing euthanasia], as I have never chosen to participate. I will always experience that internal conflict. (I 11)

Nurses perceived the patient's request as a cry for help. The irreversibility of euthanasia forced nurses to seriously consider the request rather than ignore it. The way in which patients formulated their request also influenced the degree of conflict felt by the nurses. Many patients used veiled terms when requesting euthanasia (e.g., 'Why don't you let me die?'). The nurses experienced expressions that clearly conveyed the patients' desire to die, as well as those that contained the word euthanasia, far more confronting than indirect requests (e.g., 'What's the sense of living any further?'). Caring for these patients was complicated by the fact that nurses were not able to fully understand their patients' request, deepest thoughts, and emotions. Moreover, nurses did not think euthanasia was the ultimate solution to their patients' dire predicament. Palliative care nurses, in particular, believed that euthanasia conflicts with the principles of palliative care. Interviewed nurses had difficulty in discovering the request's authenticity. It became worse if the patient was

angry and distressed. Intense emotions which could be a product of time or situation, and the patient's personality may provoke someone to request euthanasia. Such requests drifted off once the emotions tempered. The frequency with which nurses received euthanasia requests also influenced their experiences. Contrary to nurses working in regular units, palliative care nurses regularly received euthanasia requests. Participants reported that coping with such requests was a learning process. At first, the request took them by surprise: the nurses were shocked and did not know how to react. Gradually, they learned how to react to such a request. Although they were no longer as shocked as they were initially, the nurses still felt a rude awakening every time they received such a request.

> Experience also makes the difference. Initially, I thought 'Oh dear, now you're asking!' and I felt like running away. Nowadays I experience fewer difficulties and I try to explore what is behind the request. Mostly I stay calm. Sometimes I really feel powerless and I do not have clear-cut answers, but I will not run away. I stay with the patient and we will see what will come. (I 12)

3.2. Powerlessness: the central emotion experienced by participants

Powerlessness was the dominant feeling experienced by nurses. It was compounded by the presence of other feelings (anxiety, guilt, concern, distress, moral upheaval) and resulted in nurses' conflicted feelings, as already described earlier. Powerlessness was mainly caused by the nurses' inability to legally comply with the patients' request to die. Because of their personal beliefs, some nurses indicated that they would not perform euthanasia, even if it were legal. The degree of nurses' powerlessness correlated with the extent to which they were able to help their patients. They felt more powerless when patients were not informed about euthanasia or about palliative care alternatives. The sense of powerlessness was further cultivated by the nurse's relationship with the patient's relatives, who often reiterated the euthanasia request. Nurses observed that family members were apparently ill-informed about the exact meaning of euthanasia, since one of the essential conditions of executing euthanasia is that the patient himself, not others, must request it.

> I really feel powerless when confronted with a euthanasia request. People don't have the slightest idea of what euthanasia stands for … I feel powerless when confronted with the ignorance of people about things regarding themselves or when relatives propose the legalization of euthanasia. They do not realize what euthanasia is. (I 2)

We found that the nature of the nurse–physician relationship could further exacerbate the nurses' powerlessness. Some physicians did not wish to hear about the patient's euthanasia request, thereby causing nurses to feel bewildered. Nurses did not necessarily want physicians to perform euthanasia. At least they wanted them to pay attention to the request. The extent of powerlessness was associated with the amount of time that a nurse could reserve for patient care. In contrast to palliative care nurses, nurses from regular units had too demanding workloads that often prevented them from spending enough time supporting patients. Interestingly, the nurses who could empathize with their patients' suffering felt less powerless than nurses who could not empathize. However, it was rare that a nurse could fully empathize.

> I always have the feeling that we will never completely understand the request because the patient experiences such deep suffering. We understand but never fully comprehend what is going on in the depths of the patient's soul. This results in powerlessness. (I 1)

Besides powerlessness, all the nurses interviewed experienced anxiety, sometimes arising from their own ignorance; they did not know how to react to a euthanasia request. Although respecting the request, they were confronted with the illegality of euthanasia and with the hospital's euthanasia policy. Nurses working in regular units in particular felt guilt, resulting from the nurses' impression of failing in their duty toward their patient and from the lack of time for support. Nurses were also in distress, felt miserable and had to cry sometimes.

> You have a certain relationship with the patient; it always creates quite a stir. Sometimes you are sad. You are not crying all the time but there are some situations when you have a lump in your throat and you think, 'Damn, what is going on?' It isn't always easy. (I 8)

Because nurses were in a privileged care position, they also experienced positive feelings. Some nurses felt as if they were personally chosen as a trusted person towards whom the request to die was directed. This feeling increased their sense of responsibility. Nurses felt that they successfully accomplished their job, since being entrusted with such a request was viewed as confirmation of their good nursing care. Positive feelings were also influenced by the nurse's ability to talk openly about the request and about the associated emotions.

3.3. The context of nursing care

Nurses reported that the following contextual elements (negatively) affected how they dealt with the

euthanasia request: the physician's treatment aims, the care unit's consultative structure, the time allotted for patient care, the legal context, and the intern euthanasia policy. Nurses attempted to comfort their patients as much as possible. They became frustrated, however, if the physician focused primarily on curing the patient, if the physician ignored the euthanasia request or resisted palliative care support. Some nurses felt too inadequate to discuss the patients' therapeutic regimen with the attending physician. Most palliative care nurses, however, did not experience such tension. They felt comfortable discussing patient care with the physician, and as a result, both parties were able to formulate an agreeable policy of care. Another contextual element that greatly affected the nurses was the care unit's consultative structure, which consisted of four elements: the hierarchical doctor–nurse relationship, the possibility of discussing the euthanasia request, the nurse's contribution to this discussion, and feedback from the physician after his conversation with the patient. Nurses, especially PST nurses, felt that contributing to the multidisciplinary team discussion was important, because they have first-hand information about patients and their requests. The nurses felt that they were valuable partners when they actively participated in discussing the treatment plan for these patients. Because euthanasia was illegal and euthanasia requests were not regularly discussed in standard care units, nurses working in these units were more likely to feel frustrated and powerless.

> I reported the patient's euthanasia request during briefing, but then some colleagues said that we should pay attention to the patient not collecting his medication. But I thought—maybe improperly—that it wasn't our decision. I didn't speak up because it is difficult to say such things in the group. I find it hard. Such a request isn't discussed in team. We contact the PST. But the patient is left with many questions. (I 4)

Some nurses proposed that euthanasia should be legalized. This would promote open discussions about euthanasia and would lead to the formulation of clear guidelines for handling euthanasia requests. Their plea for clinical practice guidelines also was provoked by their care unit's vague policy on euthanasia and other end-of-life issues.

With high workloads, nurses in non-palliative care units felt that they could not spend enough time caring for their patients. Nurses even observed that the patients themselves sensed the hurried atmosphere and the paucity of care time; thus, they stopped asking for care. The patients did not want to bother the busy nurses with their complaints. As a result, the nurses did not register the patient's requests for euthanasia. However, even if the nurses did record the requests, it was not always possible for them to spend the desired time and energy on the patient.

> A euthanasia request can come at a very awkward time because of work pressure and business on the ward. Sometimes your patient is left alone with his question. In periods of high pressure, you try at best to pass the request to the PST. It is difficult to leave the patient behind just like that … It is an unpleasant feeling. (I 9)

On the other hand, nurses stated that a lack of time for an in-depth conversation could stimulate euthanasia requests because patients returned home with unanswered questions and doubted about the meaning of their life. Nurses also suffered from this lack of time because they had fewer opportunities to vent their grievances and feelings to their colleagues.

> You need time to talk things over with a colleague. Otherwise, it keeps haunting you. Hospitals are tied up; there is no time to vent your feelings to colleagues … Talking to patients is important. But there has to be opportunities to communicate, and that is the problem. As a nurse, you feel ill at ease with that lack of time. You would like to spend some time with that patient, but you are hindered. It is a 'lack of being' instead of a lack of time. You aren't able to be there for your patient. (I 5)

Palliative care nurses, as well as the others, reported that the palliative care setting and its associated culture created the opportunity for nurses to take the time needed to provide holistic support to patients and relatives. This time was mainly used for communicating. Because palliative care nurses cared for dying patients daily, they were considered to be experts in pain and symptom control as well as in communication. These experts were contacted as soon as possible.

> Contrary to a regular unit, we [palliative care nurses] have more time to talk to patients. … It is nice working here as you are able to work holistically. It should be common practice in other units but it isn't. There, you just don't have time for it and in a palliative care unit you do. It creates a satisfactory feeling of doing things right. Patients really appreciate when you take time. (I 13–14)

Some internal medicine nurses felt ambivalent about contacting PST nurses. They were satisfied that their patients would receive attention; but on the other hand, these nurses felt guilty when they handed over their patients to the PST nurses.

The conflict of palliative care nurses seemed less difficult, because several elements attenuated the difficulties (e.g., team support, more experience with

end-of-life care and euthanasia requests, better contact with doctors, being allowed to spend more time with patients). Nonetheless, palliative care nurses also experienced many negative feelings when caring for patients wanting to die. One PST nurse stated that she was afraid of what would happen once the euthanasia law was approved. If she were to receive several euthanasia requests each week, she would stop working in the palliative care setting (I 11). PST nurses described their ambivalent, yet difficult, position as intermediaries poised between the patients and the patient's healthcare team.

3.4. Nurses' key role in caring for patients with a euthanasia request: the process model

The interviewees stated unanimously that they had an important role in the overall care of patients requesting for euthanasia. Although summarized artificially as different stages, the phases of the care process are not strictly separable. We present it this way to illustrate the special role of nurses in each stage of this process, as described by the nurses themselves.

(a) *Period before the euthanasia request*: Although most nurses were not prepared for confronting a euthanasia request, some nurses sensed some sort of change in their patients, as if something was 'brewing up' in them. These nurses described their relationships with their patients as being so familiar that they were able to intimately talk about the patients' illness, opinions on life, coping strategies, etc. Their patients' requests to die did not surprise these nurses. During this period, the nurses mainly tried to listen and to talk to the patients to gain a better idea of the patients' mindset.

(b) *Confronting the request for euthanasia*: Irrespective of their attitude towards euthanasia, once nurses became aware of their patients' request to die, they made an effort to care for their patients in a compassionate way. If the nurse was the first caregiver to receive the euthanasia request, the nurse's most important task was to listen carefully to the patient, taking the request seriously. The function of listening was twofold: (1) to be present and to give patients the opportunity to tell their story and to express their feelings and concerns, and (2) to determine the reason(s) behind the euthanasia request. Nurses stated that many of the euthanasia requests were not real requests, but rather, were momentary or inconsistent requests prompted by either a poor quality of life or even economic reasons (e.g., being a burden). In addition to actively listening, nurses observed their patients' reactions to determine the root cause of the requests. Some nurses even discreetly confronted their patients, discussing with them inconsistencies in their reasoning, or expressed their own attitude toward euthanasia. In some cases, nurses approached either the patients' relatives or other caregivers with the aim of bringing into view the patient's request and its context. At this stage, the nurses also listened to the family members, because they also experienced conflicting emotions. All nurses indicated that certain tasks succeeded in alleviating the patients' desires for euthanasia and resulted in comforting their patients. These included listening to their patients; informing them about palliative care principles, care alternatives, and dying; reassuring them that they are there for them when needed; and maximizing pain and symptom control.

> Every euthanasia request is taken seriously, is always listened to, and is checked for the reasons behind it. Is the patient afraid of what is yet to come? Does the patient have difficult familial relations? … As a nurse, I am the caregiver who is closest to the patient, while toileting, while administering medication, while eating. So I am in the best position to observe the patient and to report the situation. (I 6)

(c) *Reporting the request to other caregivers*: The interviews showed that nurses always informed the physician and their colleagues of the euthanasia request, mostly during rounds. Sometimes the request was noted in the nursing chart. Because nurses acted as a 'sounding board' for and advocate of the patient, they considered it to be their task to acquaint the physician. Remarkably, nurses never asked themselves if they were allowed to do so without obtaining permission from the patient first.

(d) *Participating in decision-making*: In units that had no customs for debating euthanasia requests, no explicit decisions were made nor were actions taken after the nurse reported the request. In units that did have this culture, the professionals involved discussed how the request would be handled. Although the physician and the nurse (who received the request) were always involved in the decision-making, other healthcare professionals might also be present. The nurse's role in this phase consisted of supplying information about the patient's needs, feelings, and request. One PST nurse stated the importance of team discretion when discussing the request. She was divided between withholding intimate details and divulging them, the latter of which might assist the team in caring for the patient. All interviewed nurses believed it was important to have a voice in the decision-making process. They indicated that their continual and close dealings with patients foster a trusting environment in which in-depth discussions could safely take place. It was considered to be a major nursing task to communicate the significance of the patient's suffering and to relate this adequately to every team member. Besides their clarifying role, some PST nurses reported that they organized a multidisciplinary discussion to determine which healthcare

professionals should be involved in the next phase. After group discussion, physicians made the formal decision.

(e) *The result of the decision-making process*: Nurses stated that a patient's request for euthanasia was never actually executed by nurses themselves. With the physician's help, nurses at times tried to enhance the terminally ill patient's dignity and to maximize their comfort by medically controlling pain and symptoms. The possibility of referring a patient to another hospital that performed euthanasia was mentioned in theory, but occurred only once. Palliative sedation was another often-mentioned solution to comfort the patient, but it was only performed if the patient persisted in his euthanasia request in spite of pain and symptom control. Especially during this phase, nurses supported the psychosocial needs of their clients. They tried to ease the patients' mind by informing them about practical things and encouraged them. Their supportive role toward the relatives primarily consisted of listening to them express their feelings, just silently being present.

(f) *Aftercare*: The interviewed nurses reported no cases of euthanasia actually being carried out, but they did state that they played an important role in supporting the patient's family once the patient passed away. Nurses would talk to the relatives to help them grieve.

3.5. Caring for themselves and their nursing colleagues

Nurses were in a privileged position in their care of patients requesting euthanasia, but on the other hand, this caring process resulted in an internal conflict. To cope with this, nurses cared for themselves using several strategies. As professionals, nurses' sympathy extended to their patients, but a certain emotional distance was maintained. Many nurses underlined the importance of psychologically releasing the patient's request. Not all nurses succeeded in maintaining this emotional distance. Another strategy was to carefully watch their limits, for instance, by stating that administering the lethal drugs was a medical act beyond their competence. When nurses felt they were not psychologically capable of talking to their patients about euthanasia, they openly admitted it to them. Some nurses related that they tried to compensate for their negative feelings by making the most of the short time with their patient. Nurses' coping process was facilitated when they were satisfied with the physician's ultimate decision on the handling of the euthanasia request. Although not always having the opportunity, nurses found it important to be able to express their feelings to their colleagues, as it relieved their tension and allowed them to go on with their job and life. Non-palliative care nurses in particular took their experiences home after their shift. Being members of a close team, nurses received much emotional and practical support from their colleagues. The feeling of not being on one's own was reported as an advantage of teamwork. Moreover, it allowed colleagues to confirm that the nurse handled the situation well. This confirmation enhanced the nurse's coping process. Nurses prevented each other from getting too involved. This solidarity engaged not only when a nurse became too emotionally close to patients, but also when a nurse lacked the expertise. In these situations, colleagues took over their tasks.

> It's troublesome when you get too close to patients. We decided, as a team, to look out for each other, to keep an eye on one's limits. If someone exceeds these boundaries, we will take over the care from that colleague. (I1)

4. Discussion

Although we interviewed the participants when euthanasia was illegal and our findings were limited to the Belgian situation prior to euthanasia legalization, our research showed that nurses are involved in the care process for patients requesting euthanasia. The nurses we interviewed seldom felt completely in favor of or completely against euthanasia. This indifferent view caused the nurses to have ambivalent feelings when confronted with a patient's request to die. The difficulties that the nurses experienced had to do with the complexity and contextual nature of euthanasia and dying. Indeed, as recently reported by Verpoort et al. (2004b), unlike the general population, nurses are less likely to view euthanasia according to strict 'black and white' terms. We found that nurses were the first caregivers to receive patients' requests for euthanasia. Review of literature from the USA and Australia confirms this observation, indicating that approximately one in four nurses have been confronted with a euthanasia request (De Beer et al., 2004). Qualitative research from the Netherlands shows that half of the patients use the word 'euthanasia' to express their request, while the other half use vague terms (van de Scheur and van der Arend, 1998). The nurses whom we interviewed also mentioned that many patients formulated their request either indirectly or using veiled terms. Thus, an important role of nurses is to determine whether the patients' requests are understood and interpreted correctly. The nurse is not just an intermediary. We found that the nurses used their expertise stemming from the daily care of terminally ill patients to assess the validity of the euthanasia request or to determine whether the request represented some other appeal for help. In addition, we found that the nurses listened carefully to the patients recount their experiences with the aim of gaining more insight into the patients' motivations for euthanasia. This is consistent

with the observations of van de Scheur and van der Arend (1998). Although the nurses in our study generally empathized with their patients' requests, they seldom understood completely why the patients had requested to die. Contrary to the findings of the Dutch study (van de Scheur and van der Arend, 1998), we found that our nurses' ability to empathize with their patients' requests did not depend on their attitude towards euthanasia. Regardless of their personal views, the nurses whom we interviewed stated that they were deeply touched by their patients' inhumane suffering.

The nurses we interviewed stated that they always informed the attending physician and their nursing colleagues about patients' requests to die. In most cases, however, they did this without asking their patients' permission, indicating that the nurses may not have been sufficiently aware of the need to carefully handle sensitive topics such as euthanasia. van de Scheur and van der Arend (1998) encountered the same lack of awareness in the nurses they interviewed. In contrast to the Netherlands (KNMG & NU'91, 1997), in Belgium, no guidelines presently exist that require nurses to obtain their patients' permission to inform other caregivers of their wish to die. In care units that had well-defined euthanasia policies, we found that the healthcare professionals involved discussed how such requests would be handled. The nurses stated that their role in these discussions was to supply other team members with salient information about the patient that could be obtained only as a result of their close and often physical dealings with the patient. Examination of literature based on quantitative studies or data collected through physician self-reports, however, reveals that, in about half the cases did, Belgian nurses participated in discussions dealing with euthanasia or assisted suicide (Deliens et al., 2000; Bilsen et al., 2004; De Beer et al., 2004). In the present study, we noted differences in the extent to which physicians consulted with nurses. Nurses suggested one possible explanation for this lack of communication: the nursing care context. Time pressure, setting (e.g., palliative care vs. regular care), physician specialty (e.g., oncology), and hierarchical doctor–nurse relationships were all frequently mentioned as contextual elements that influenced whether nurses participated in decision-making on euthanasia.

Although Deliens et al. (2000), and most recently Bilsen et al. (2004), revealed that Belgian nurses participate in performing euthanasia, the nurses of our study—perhaps because of the illegality of euthanasia—did not report a single request that ended in euthanasia. Of course, this does not mean that euthanasia does not occur in Belgium. Some estimate that 0.3% (van der Heide et al., 2003) to 1.1% (Deliens et al., 2000) of deaths in Flanders result from euthanasia. A retrospective study indicates that Belgian nurses themselves administer lethal drugs in more than half of the euthanasia cases (Bilsen et al., 2004). It is not clear whether these nurses were aware of the impact of their acts. Since these findings were based exclusively on the reports of the physicians involved, their results could be biased. Moreover, the questionnaire used in this study contained a limited number of questions about the nurses' involvement in euthanasia. The study that cries out to have been done alongside the study of Bilsen et al. (2004) is a qualitative study that uses in-depth interviews to determine the nurses' reactions in these situations. Our interviews indicated that the nurses attempted to enhance the dignity of terminally ill patients and to maximize their comfort level by controlling their pain and symptoms. The nurses primarily focused on giving psycho-social support to the patients and their relatives. They tried to ease their clients' minds by listening attentively, informing them, reassuring them that they will be there for them when needed, as well as giving patients effective medications. The nurses foresaw that their role of supporting the patient's family would continue beyond the patient's death. This is consistent with the findings of Demarest and Bend (2004).

Although the participants had many significant roles while caring for patients requesting euthanasia, they experienced feelings of powerlessness, anxiety, guilt, concern, moral upheaval, and grief. Among these feelings, powerlessness was the most predominant, resulting from various issues associated with the nature of the euthanasia request, the nurse, and the nursing care context. As the interviews demonstrated, nursing care context differed greatly in palliative care and regular care settings. Because nursing care context was the only element to definitely affect the nurses' experiences, this element must be optimized. Nurses became frustrated if the attending physician focused on curing patients and if the physician was not receptive to palliative care alternatives. Euthanasia was still illegal in Belgium at that time. Thus, practices associated with euthanasia, as well as the partially related fact that the euthanasia was not commonly discussed in care units, increased the nurses' feelings of frustration and powerlessness. In regular care units, when the workload was high, nurses felt guilty that they did not have enough time to care for their clients. This situation either encouraged or discouraged patients to ask for euthanasia. It is noteworthy that all the participating nurses stressed that the palliative care setting and its associated culture (group mentality, care philosophy) created the opportunity for nurses to take time to holistically support patients and their relatives. Besides the fact that palliative care nurses had more experience with end-of-life care and euthanasia requests, their difficult role in caring for these patients seemed to be tempered by the supportive palliative care context. Remarkably, we found that the care unit where the patient is hospitalized and its associated contextual elements significantly

influenced the quality of nursing care that patients received. This result corroborated the literature review of De Beer et al. (2004). Our study revealed that the unit's workload prevented nurses from expressing their feelings to colleagues. Nevertheless, they listed venting one's feelings as an important strategy to remain emotionally balanced. Working in a team, as those clearly present in palliative care settings, caused the nurses to feel that they were not on their own and enabled them to stand in for a colleague when needed. We did not observe this feeling of solidarity in units where euthanasia was unmentionable. These nurses felt isolated, which is consistent with the findings of Matzo and Schwarz (2001). Our findings also indicate that each stage of this process requires that the nurses possess specific supporting competencies. Their willingness to personally care for these patients, in addition to their specific care expertise, allows them to be skilled companions (Titchen, 2000). This could explain the positive feelings that our nurses described. Such a companion is competent to ascertain the patient's needs and willingly works in concert with the patient and the team to seek the most dignified answers to the patients' questions about euthanasia.

4.1. Methodological issues

Although we initially sought to integrate as much heterogeneity as possible in our sample, recruitment was difficult. We delegated the selection of participants to an internal contact person, but it turned out that they were too busy to spend adequate time assessing potential participants. This was compounded by the limited availability of nurses willing to cooperate, probably because the study was carried out in the period when euthanasia was illegal. We therefore expanded the study's inclusion criteria. Our final sample was small but fairly heterogeneous with regard to the nurses' personal characteristics. Despite these limitations our results remain valid because the study was carried out in three general hospitals, saturation was achieved, and built-in guarantees were present to ensure the trustworthiness of data. These mitigating factors ensured that our data would yield a better understanding of the experiences of nurses who care for patients requesting euthanasia in Belgian hospitals.

4.2. Implications for clinical practice

The nurses' reports contrast sharply with the almost total absence of nurses in the euthanasia debate worldwide. Some nurses advocated the legalization of euthanasia to promote an open discussion. Their call for clear practice guidelines was also prompted by the vagueness of their units' current euthanasia policies, as well as by other contextual elements. Research into the actual involvement of nurses—as explored here—will be useful when drawing up uniform practice guidelines for euthanasia, particularly with regard to physician–nurse communication. Although legally mandated (Ministry of Justice, 2002), there are no formal guidelines for the content of this communication. Administration of lethal drugs by nurses was and is legally prohibited, and this has been affirmed by professional nursing guidelines (WVVV, 2003). Unfortunately, there is little practical guidance for a nurse caught between a patient's euthanasia request and a medical order. Besides, professional guidance needs to move beyond role clarity to include skill development in exploring expressed desire to die, and team skills that empower nurses to discuss the management of these patients. These strategies can reduce the unjustified variation in patient care, as well as the uncertainty about the nurses' role in euthanasia, and can maximize the care context and promote high-quality nursing care. Such findings present a strong argument to include ethics, legal, and health policy issues related to end-of-life as part of the standard nursing curriculum.

4.3. Further research

Research with regard to the actual role of nurses caring for patients requesting euthanasia is in its infancy, but it is developing. The present study offers an opportunity to reflect on the nurse's role in relation to the popular opinion worldwide that euthanasia is an appropriate component of end-of-life care. Our study provides a baseline for future studies (quantitative and qualitative) aimed at refining nurses' experiences with euthanasia. Besides, it will be interesting to see whether their experiences change as euthanasia becomes legalized. Research in other regions and practice settings in Belgium, and other countries would add to the present study. Because euthanasia is a value-laden issue, comparing our results with the empirical results of studies in one of the countries where euthanasia is still illegal would add significantly to our knowledge.

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